

Arkansas

Spinal Courier

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Kent Waldrep to Speak at SCI Seminar

Kent Waldrep will be the keynote speaker at the June 8, 1990 seminar on spinal cord injuries to be held in Little Rock. Kent is the founder, president, and CEO of the Kent Waldrep National Paralysis Foundation, a non-profit charity dedicated to supporting paralysis research and providing services to the paralyzed community. He has appeared on numerous radio and television shows and has had feature articles in several national periodicals. He is currently serving his fourth term on the National Council on Disability, a Presidential appointment.

Entitled "Living with Spinal Cord Injuries in the 90's," the seminar will provide a unique experience combining the knowledge of

skilled health professionals with the life experiences of persons who are coping with spinal cord injury. The program will include sessions on spinal cord injury surveillance, pressure sores, coping and advocacy, leisure activities, sexuality, technology adaptations, and wheelchair repair.

Holiday Inn West is the site for the seminar and handicapped rooms are available for those desiring to stay overnight. The registration fee is \$10 for persons with spinal cord injuries/ASSCC clients/family members and \$25 for Health Care Professionals. For a registration form and more information, contact Loretta Decker at (501) 371-3011.



The Arkansas State Spinal Cord Commission is sponsoring this state-wide educational seminar in cooperation with the Centers for Disease Control.



Camp Aldersgate Means Fun!

Mention Camp Aldersgate to any child who has been there and you'll get an ear full: swimming, parties, cookouts, boating, horseback riding and more. Camp not only provides a wide range of scheduled activities but it provides a growing experience for the child and parent as well.

The dates for camp this year are June 10-15 for ages 12 through 16 and July 1-6 for ages 6 through 11. Camp is open to young ASSCC clients with spina bifida and other spinal cord disabilities. All camp buildings are wheelchair accessible and air conditioned. Twenty-four hour medical coverage is provided and all campers receive one-

to-one supervision by trained counselors and volunteers.

Application forms have already been mailed to prospective ASSCC campers and need to be returned by May 18, 1990. If your child did not receive an application, please call Betty Massey, ASSCC Camp Coordinator at (501) 371-1283.

The Arkansas State Spinal Cord Commission is sponsoring these two week long sessions in cooperation with MedCamps of Arkansas, Aldersgate Methodist Camp and Spina Bifida Association of Central Arkansas.

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Cheryl L. Vines
Executive Director

Thomas L. Farley
Editor

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BUCKLE UP!

Wheelchair Fishing Derby

The Arkansas State Spinal Cord Commission and the Arkansas Game and Fish Commission are jointly sponsoring a wheelchair fishing derby on Crown Lake at Fisherman's Park, in Horseshoe Bend, Arkansas on Saturday, May 26th from 10:00 a.m. to 6:00 p.m.

You and your family are cordially invited to attend. Lunch will consist of grilled hamburgers and hot dogs. The evening meal will be catfish with all the trimmings. To plan for adequate food and drinks please RSVP to Charles Crowson at 793-4153. Thanks.

Bring your fishing pole and join the fun!

Spina Bifida Association to Meet

The Spina Bifida Association of America will hold its annual conference June 20 - 23, 1990 in Memphis, Tennessee. For more information regarding registration, conference program and accommodations please call 1-800-621-3141.

AUTONOMIC DYSREFLEXIA

by
Shirley McCluer, M.D.

Autonomic dysreflexia is a potentially life threatening condition that only occurs in individuals who have spinal cord injury at the T6 level or higher (quadriplegia and high paraplegia). Most doctors have never heard of it and therefore do not know how to recognize or treat the condition when it occurs. For this reason it is very important for anyone with a spinal cord injury who might be subject to autonomic dysreflexia to understand it thoroughly and be able to explain it to doctors and emergency room personnel when necessary.

Symptoms-The first symptom is usually profuse sweating of the face and shoulders. This is more annoying than serious. However, this is sometimes followed by a pounding headache caused by a sudden sharp increase in blood pressure (BP). This high blood pressure can cause seizures, stroke, or even death in extreme cases. Since all headaches are not due to autonomic dysreflexia, it is advisable for all quadriplegics to be able to check their blood pressure at home.

Cause-The most common cause is bladder fullness or bladder spasms, but it can be caused by constipation, bowel program, decubiti, etc. In general, the cause is something that would normally be painful but is located below the injury and therefore a person with spinal cord injury cannot feel the pain.

Treatment-The most important treatment is to Eliminate the CAUSE! Therefore it is necessary to know what to look for. The blood pressure usually drops immediately (within 2-3 minutes) after the cause is removed.



Frequency-For some individuals episodes may occur several times a week and for others it may occur only once in several years.

If you think you may be having autonomic dysreflexia, it is recommended that you contact your case manager for more detailed information. You should give a copy to your physician and keep a copy where you can locate it in an emergency!

Methylprednisolone Not New

by
Shirley McCluer, M.D.

Many of you have probably seen the news release recently regarding use of Methylprednisolone in acute SCI. The ASSCC is gathering more information about this and will report to you later. However it is important that you keep the following in mind:

1. This will have no effect on existing spinal cord damage. It must be used within 8 hours of injury to prevent further nerve destruction after the initial impact.
2. This is not a new treatment. It has been used by many physicians for a number of years. The primary difference is how and when the medication is given.

Further details will be reported later.

THE BALLAD OF MULTIPLE SCLEROSIS

❖
To my mother:
Charlotte Diann Miller
❖

Excited over the baby,
the symptoms were ignored.
Fatigue took the life out of her
as she cared for her newborn.

A mother she could never be,
maternal dreams destroyed.
Her daughter's friendship unfulfilled,
her health is her son's void.

She seemed okay until fall came:
the doctor didn't know.
Neuritis struck her eyes again:
her eyesight started to go.

Her health declined the following
year,
confusion seemed to build.
Away from her, he took her youth,
and never stopped to yield.

A mother she could never be,
maternal dreams destroyed.
Her daughter's friendship unfulfilled,
her health is her son's void.

Her health returned for one whole
year:
her spirit she regained.
The summer filled with only sports
and not a drop of rain.

The pain came back to end the fun
to bring the clouds again,
and she began to realize that
she could never win.

A mother she could never be:
maternal dreams destroyed.
Her daughter's friendship unfulfilled,
her health is her son's void.

Leann Miller

You've Got to Have Dreams



"You've got to have dreams," according to Dale Tabor, of Harrison. "If you don't, you have nothing to hope for." That's his philosophy. It's not just something he says either. Dale has been living it since he was paralyzed in 1969 in an automobile accident. "You have to accept yourself where you are," he added. Tabor graduated from Pyatt High School where he was a basketball star and attended Arkansas Tech for one year on an athletic scholarship. He had hoped to be a coach some day. In a fraction of a second on August 16, his life and all his dreams changed. His dreams didn't die -- they changed.

In a coma for three months, Dale's recuperation was long and an uphill battle. It was two more years before he tried his skills at painting, something he had dabbled in since fifth grade. He found that because of his restricted movement in his arms, painting with his hands was difficult. He spent the next six years trying to develop a style that would be easier for him. He had read about "mouthstick" painting and decided to try it. His efforts paid off. He began selling his paintings and in 1977 received

a scholarship to the Charles Glassco School of Art in Houston. "At the school, I found the style that was best for me and I knew that painting was my future." Dale spoke of the frustration a person feels after becoming disabled. It is so hard to find yourself after an injury. You fight yourself, the injury, and the depression. Painting took me out of that."

Dale's success has continued. Today, he sells almost all of the paintings he does. He has had paintings displayed in cities across the United States and in some foreign countries. He has tried painting a variety of scenes and portraits, but, he prefers landscapes and nature. Dale says he spends 7-10 hours a day painting when he is preparing for a show, but may not paint at all on some days.

When asked about a particular highlight in his life, Dale quickly said that being accepted by the MOUTH AND FOOT ARTISTS OF THE WORLD was the most exciting thing. He sends work to them every year and they provide support and monitor his study. This association, based in Switzerland with an affiliate in Buffalo, N.Y. selected Dale as one of four persons to spend a week in Colorado on a float trip. Three attendants were provided to accompany each artist. The purpose of the trip was to provide experiences these people would not normally have.

Dale has a full schedule. Even when he is not painting, he often finds himself speaking to students in local schools. He not only tells kids to keep dreaming, but he shows them how to do it. He shows them that when one dream is stopped, you can always find another.

Toll Free Social Security Inquiry

Gwendolyn King, the Social Security Administrator, said in Washington that the agency's toll-free telephone service has been expanded to cover the entire country. She said recipients can dial 1-800-234-5772 around the clock every day of the year to obtain information on social security benefits or problems.



ASSCC Services Offer More Than Financial Aid

"I don't meet ASSCC's financial criteria so there's nothing my case manager can do for me!" This misconception is often voiced by individuals with spinal cord disabilities. Many never realize the ASSCC case management system is able to provide a multitude of services which are not restricted because of the "family's income."

A continuum of specialized services is available to every individual meeting medical criteria. These services include: counseling, referral to other appropriate agencies, advocacy, technical assistance in areas such as: home modification plans, ramp construction, guidance in developing realistic goals for the future, establishing support groups, and obtaining resource material. It is the case manager's responsibility to assist with and provide services which enable individuals with spinal cord disabilities to establish and maintain their maximum potential for independence and productivity in the community.

The case manager is a trained professional who promotes case coordination and alleviates the family's frustrations by intervening on their behalf whenever necessary.

Learning to cope with unexpected problems, appropriately utilizing community resources and effectively securing the services necessary to meet one's needs can be emotionally overwhelming for an individual or his family. The ASSCC Case Manager can provide support, confidence, encouragement and will often help minimize conflict.

Remember, make your case manager aware of your needs, utilize their knowledge and skills and let them become your best allies. Sometimes the best things in life are free!

INDEPENDENT LIVING TECHNOLOGY

Some people may look at their wheelchairs and say a few choice curse words. I prefer to think of mine as a tool of independence. Without it, I'd be like a plant, waiting for someone to come along to water me and set me in the sunshine. There are other devices and gadgets like speaker phones, remote control units, reachers, etc. that can increase independence and give that important feeling of "usefulness," being a part of the rest of the world, and even allowing one to play. Whatever one's disability or age, from toddler to

senior citizen, the Technology Center for Independence (TCI) can provide free information about independent living technologies in the following areas: Personal Care, Home Health, Home Management, Architectural Modification, Recreation, and Transportation.

If you have a desire to increase your independence in one of the above areas or you have a question about a particular device (regarding price, nearest vendor, funding, etc.) call or write Doris Culver at Life Styles/Technology Center for Independence, P.O. Box 1114, Fayetteville, AR 72702, phone (501) 521-8476. We serve all of Arkansas.

Americans with Disabilities Act

Rally in support of ADA Saturday May 19, 1990, 10 a.m. to 12 noon on the steps of the State Capitol.

If we want to be fully entitled and recognized citizens of this country and have the same rights as afforded every other citizen let your voice be heard. Music and guest speakers provided.

For more information contact Ann Gallmeyer, Mainstream Living, 371-0012 (TDD 372-3575).

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Arkansas State Spinal Cord Commission
Medical Arts Bldg., Suite 207
1120 Marshall Street
Little Rock, AR 72202

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